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No. 88-1503

IN THE

Supreme Court of the United States

October Term 1989

NANCY BETH CRUZAN, et al.,
Petitioners,

v.

DIRECTOR OF MISSOURI DEPARTMENT OF HEALTH, et al.,
Respondents,

v.

THAD C. MCCANSE, Guardian ad litem,
Respondent.

On Writ Of Certiorari To The Missouri Supreme Court

BRIEF AMICI CURIAE OF THE ASSOCIATION FOR RETARDED CITIZENS OF THE UNITED STATES, THE ASSOCIATION FOR PERSONS WITH SEVERE HANDICAPS, THE ETHICS AND ADVOCACY TASK FORCE OF THE NURSING HOME ACTION GROUP, AND THE MEDICAL ISSUES TASK FORCE OF THE UNITED HANDICAPPED FEDERATION IN SUPPORT OF RESPONDENTS DIRECTOR OF MISSOURI DEPT. OF HEALTH, ET. AL.

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QUESTION PRESENTED

Is a State required under the United States Constitution to authorize court-appointed guardians to cause the death of their incompetent and dependent ward by denying her food and fluids when she is not terminally ill and assuming there is no clear and convincing evidence of her intent?

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INTERESTS OF AMICI CURIAE

The Association for Retarded Citizens of the United States (ARC) is the largest voluntary organization in the United States devoted to securing the rights of, and effective services for, the approximately 6,000,000 citizens with mental retardation in this nation. ARC has a national membership of more than 160,000 people. Members include persons with mental retardation and their parents. ARC has approximately 1,300 state and local chapters throughout the country. Members of Congress, state legislatures, rulemaking authorities, and the courts recognize ARC as a leading advocate for citizens with mental retardation. Since 1973, ARC has publicly and uniformly condemned the practice of withholding nutrition and hydration on the basis of mental disability. *See* Appendix A.

The Association for Persons with Severe Handicaps (TASH) (formerly the American Association for the Education of the Severely/Profoundly Handicapped) was founded in 1974 to develop, advocate, and implement laws to benefit individuals with severe or profound disabilities. TASH strongly opposes any approach authorizing third-party decisionmaking to forgo nutrition and hydration from incapacitated persons on the basis of mental disability. *See* Appendix B.

The Ethics and Advocacy Task Force of the Nursing Home Action Group advocates needed medical care and treatment for residents of nursing homes and long-term care facilities. Such persons are vulnerable to discrimination based on disability, illness, age, or unjust economic priorities. The Ethics and Advocacy Task Force is a committee of the Nursing Home Action Group, a non-profit corporation with membership throughout the United States. Founded in 1983, the Nursing Home Action Group promotes the rights and interests of nursing home residents through legislation, advocacy, counseling, and networking. The majority of members of the Ethics and Advocacy Task Force have permanent physical or mental disabilities and are indigent.

The Medical Issues Task Force of the United Handicapped Federation (UHF) has participated as an amicus in several court cases involving threats to the provision of treatment and care for persons with disabilities. The United Handicapped Federation is a national disability rights coalition of 51 organizations with over 15,000 individual members. The UHF Board of Directors resolved in 1986 that full access to food and fluids, including sustenance administered by artificial means, is a basic right of all persons regardless of age or disability. *See* Appendix C.

The parties have consented in writing to the filing of this Brief. Copies of the written consents are on file with the Clerk of the Supreme Court.

SUMMARY OF ARGUMENT

The Missouri Supreme Court placed appropriate substantive and procedural limits on the authority of state-appointed guardians to make medical decisions on behalf of incapacitated persons. These safeguards protect the lives and well-being of all similarly vulnerable persons with mental disabilities.

The Missouri court's ruling is consistent with accepted constitutional norms, federal and state law, and sound public policy. The court correctly held that a ward's individual liberties may not be fully exercised by state-appointed guardians. The right of guardians to make decisions governing the disposition of incapacitated adults stems from the state's authority to act in the ward's best interests. The nature and history of guardianship law amply support the Missouri court's conclusions. Petitioners' counter-assertion of constitutional authority to withhold food and fluids from Ms. Cruzan would imperil the lives and well-being of all incapacitated persons whose care depends on the conduct of guardians or other surrogates.

The Missouri Supreme Court was free under the United States Constitution to require state-appointed guardians to act pursuant to a strong interest in the preservation of life. Likewise, the court properly considered the non-burdensome nature of providing food and fluids by tube to Ms. Cruzan. The court's reasoning prevents "quality of life" assessments from being employed that would endanger the lives and well-being of all persons with long-term mental disabilities.

Finally, the Missouri Supreme Court decision comports with federal constitutional guarantees, Congressional policy, and particular laws of the states. The court correctly recognized the overriding value of Ms. Cruzan's right to live and her right to equal protection of the law. Similarly, the court's decision mirrored Congressional and state laws by refusing to apply a standard of care based on level of disability and by refusing to authorize the withholding of food and fluids without the express consent of Ms. Cruzan.

ARGUMENT

I. The Missouri Supreme Court Ruling Should Not Be Disturbed; Reversal Would Thwart The Efforts Of States To Protect Persons With Mental Disabilities And Would Jeopardize The Life And Well-Being Of Not Only Ms. Cruzan, But All Similarly Vulnerable Persons.

The outcome of this case potentially threatens the lives and well-being of countless numbers of persons with mental disabilities in the United States.

There are more than 10,000 people in the United States with Ms. Cruzan's condition; all require assistance in obtaining sustenance. Brief of *Amicus Curiae* American Academy of Neurology In Support of Petitioners at 3. But the circle of similarly vulnerable persons extends much wider. An estimated 1.5 million Americans have severe dementia, and this population is expected to increase 60 percent by the year 2000. Office of Technology Assessment, Congress of the U.S., *Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias* 3 (1987). In addition, 750,000 to 1,000,000 persons have Alzheimer's Disease. Martin, *Update on Dementia of the Alzheimer Type*, 40 Hospital & Community Psychiatry 593 (1989). Four out of every 10,000 (or approximately 100,000) persons in this country have autism. Ritvo, Freeman, Pingree, Mason-Brothers, Jorde, Jenson, McMahon, Petersen, Mo & Ritvo, *The UCLA-University of Utah Epidemiologic Survey of Autism: Prevalence*, 146 Am. J. Psychiatry 194, 199 (1989). Finally, Americans with mental retardation number as many as 7.5 million persons. Munro, *Epidemiology and the Extent of Mental Retardation*, 9 Psychiatric Clinics of North America 591, 597 (1986). Like Ms. Cruzan, many of these persons are incapable of making decisions regarding their treatment or care.

At minimum, 848,100 people each year in the United States receive tube (enteral) feeding as a "life-sustaining technology" in hospitals, nursing homes, and in their homes. Office of

Technology Assessment, Congress of the U.S., *Life-Sustaining Technologies And The Elderly* 294 (1987). Of the 35,518 nursing home residents in the State of Missouri, 13,771 require some form of assistance in consuming nourishment; an additional 1,159 receive nutrition and hydration by tube. Correspondence from William Crochunis, Health Care Financing Administration, U.S. Dept. Health and Human Services, to Teresa Kealy (Aug. 29, 1989). There are 437,634 nursing home residents in the United States who require some form of assistance in consuming nourishment. *Id.* An additional 35,873 receive nutrition and hydration provided by tube. *Id.* In California alone, almost two thirds (63%) of the 6,880 residents in state facilities for persons with developmental disabilities require full or partial assistance in eating. *See* Brief in Opposition to Motion for Preliminary Injunction, Appendix C, *Sanchez v. Fairview Developmental Center*, No. CV 88-0129 FFF (Tx) (C.D. Cal. filed Feb. 22, 1988) (on Mar. 30, 1988, court denied motion for preliminary injunction filed by parents/guardians seeking to terminate provision of food and water through a gastrostomy tube to ward in "light comatose" state). *See generally*, Johnson, *Witholding Fluids and Nutrition; Identifying the Populations at Risk*, 2 Issues L. & Med. 189 (1986).

For this Court to hold with the Petitioners and against the decision of the Missouri Supreme Court, it must decide that the United States Constitution places the interests and very lives of these people virtually in the hands of their guardians or other surrogates without affording the wards any significant state protection. To the contrary, as your amici will show, the Constitution fully supports the reasoning of the Missouri Supreme Court's decision.

II. The Missouri Supreme Court Ruling Is Consistent With The United States Constitution And Long-Standing Legal Tradition Governing The Disposition Of Mentally Incapacitated Adults.

Mentally incapacitated persons such as Ms. Cruzan retain

rights and liberty interests under the Constitution. *See Parham v. J.R.*, *442 U.S. 584, 600 (1979); Thompson v. Oklahoma*, 108 S. Ct. 2687, 2693 n.23 (1988); *DeShaney v. Winnebago Dept. of Social Services*, 109 S. Ct. 998, 1002-03 (1989). The State may not subject these persons to unnecessary confinement or unwarranted treatment. *Parham v. J.R.*, 442 U.S. 584, 600 (1979). One way that the State affords protection to persons with disabilities is through the appointment of guardians, sometimes family members, to act in the best interests of their wards. *In re Phillip B.*, 139 Cal. App. 3d 407, 419, 188 Cal. Rptr. 781, 788 (1983). Parents have independent rights in the custody and control of their *minor* children. *Lassiter v. Department of Social Services*, 452 U.S. 18, 27 (1981). Parents or others in special circumstances may have *standing* to assert the rights and interests of others. *Youngberg v. Romeo*, 457 U.S. 307, 309-10 (1982) (guardian/parent has standing); *In re Quinlan*, 70 N.J. 10, 34, 42, 355 A.2d 647, 660-61, 664, *cert. denied*, 429 U.S. 922 (1976). (guardian has standing to assert incapacitated person's rights, but no independent right of his own).

This Court has never held, however, that the liberty interests of one person are wholly transferred to a surrogate, by operation of constitutional law, when the person is unable herself to exercise them. Rather, this Court has held only that the personal liberties enjoyed by persons incapable of making their own decisions may only be "meaningful" when "exercised by agents *with the best interests* of their principals in mind." *Thompson v. Oklahoma*, 108 S. Ct. at 2693 n.23 (emphasis added).

Here lies the heart of the urgent controversy now before this Court: What are Ms. Cruzan's best interests, and who determines them?

The Missouri Supreme Court held that Ms. Cruzan's guardians would exceed their otherwise legitimate statutory authority by refusing her food and fluids because this would not be in Ms. Cruzan's best interests. The court based its holding on a careful evaluation and balancing of state public policy consid-

erations, constitutional values, the logic of conflicting claims — and finally and most importantly on its belief that care provided by "artificial hydration and nutrition" is not "oppressively burdensome to *Nancy* in this case," especially since death was the inevitable consequence of nontreatment. *Cruzan v. Harmon*, 760 S.W.2d 408, 423-24 (Mo.banc 1988)(emphasis in original). Rather, sustenance is more properly to be regarded as a benefit to Ms. Cruzan — an act of caring and compassion for another.

The Petitioners as guardians [hereinafter "guardians"] argue, however, that "[s]ince Nancy can no longer speak and since she did not execute express directives before her accident, her right to have her family or any other surrogate decisionmaker participate in her medical treatment decisions, and her right to be free from unwarranted, state-ordered physical invasion of her body, are lost in Missouri." Brief for Petitioners at 20 [hereinafter "P.B."]. The United States Constitution, they claim, demands a different result: "the right to have . . . [the] decision [to withhold food and fluids from her] made by an appropriate surrogate decisionmaker — her family." P.B. at 29.

Assuming the validity of the Missouri Supreme Court's finding that there was no clear and convincing evidence of Ms. Cruzan's intention regarding the provision of food and fluids to her,[1] your *amici* argue that the Constitution provides no sup-

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[1] Your amici take no position on whether or not the Missouri Supreme Court properly concluded that there was insufficient evidence regarding Ms. Cruzan's intent regarding the provision of food and fluids to her. The clear and convincing standard of proof required by the Missouri court is, however, appropriate in view of the constitutionally protected rights at stake in declining sustenance necessary for life. *See* this Brief at 20-23. *Brady v. United States*, 397 U.S. 742, 748 (1969)("waivers of constitutional rights must be knowing, intelligent acts done with sufficient awareness of the relevant circumstances and likely consequences"); *Fuentes v. Shevin*, 407 U.S. 67, 94 n.31 (1971)("in the civil no less than the criminal area, courts indulge every reasonable presumption against waiver [of constitutional rights]."); *Addington v. Texas*, 441 U.S. 418, 433 (1979) ("clear, unequivocal and convinc-

(footnote continued)

port for the guardians' attack on the Missouri court's decision.

Ms. Cruzan's liberty interest in refusal or *acceptance* of a "bodily intrusion" necessary to prevent death by dehydration and malnutrition is not "lost" in Missouri as the result of that state's Supreme Court decision. She is unable to exercise her interest in one way or the other as the result of her accident. If her liberty interest is to be "meaningful" at all, therefore, then it must be exercised by another in her best interests. Her guardians claim that the Constitution bestows upon them the unreviewable authority to exercise her right to refuse food and fluids. They urge that the "state should not be involved at all" in this decisionmaking (P.B. at 39), and their position would bar any judicial review in cases such as this. The Missouri court, as the final arbiter of Ms. Cruzan's best interests, determined that it was not in her interests to die from lack of sustenance.

The liberty interest in refusing bodily intrusions claimed by Ms. Cruzan's guardians against the Missouri court decision is exceedingly broad, arising from the common law rule that *any* unconsented touching is battery. *See* Byrn, *Compulsory Life-saving Treatment for the Competent Adult*, 44 Fordham L. Rev. 1, 5-6 (1975). If this liberty interest may be exercised by a surrogate without supervision by civil authority, then the surrogate might not only be empowered to refuse food and fluids,

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Footnote 1 continued

ing" burden of proof must be met before guardian can waive another's constitutionally protected freedom against confinement). *See also In re Westchester County Medical Center (O'Connor)*, 72 N.Y.2d 517, 532 n.4, 534 N.Y.S.2d 886, 893 n.4, 531 N.E.2d 607, 614 n.4 (1988)(clear and convincing evidence standard is appropriate burden for proving an intent to refuse life-sustaining care since "there are numerous instances in which the law refuses to recognize the exercise or waiver of an important right unless the intent to do so is clearly manifested"); *In re Peter*, 108 N.J. 365, 378, 529 A.2d 419, 425 (1987)(clear and convincing standard applied to determination of patient's treatment preferences); *Leach v. Akron General Medical Center*, 678 Ohio Misc. 1, 11, 426 N.E.2d 809, 815 (1980)("because of the nature and importance of the issues involved, this court would be remiss if it did not adopt the highest possible civil standard of clear and convincing").

but also, in principle, reject any form of treatment or care. Ms. Cruzan, were she competent, could refuse to eat by spoon or drink by straw; she could refuse to be turned to prevent bed sores; she could refuse a single aspirin even if this were all that were necessary to restore her to full capacity and health. And if Ms. Cruzan's liberty to consent to care or to refuse care were fully exercised by her guardians, then her guardians would be likewise free to refuse "any touching" of Ms. Cruzan. Such authority would expose countless persons to the idiosyncratic predilections of their guardians and other surrogates. It would risk the termination of treatment and care of all kinds for whole populations of incapacitated people. *See, e.g., In re Phillip B.*, 139 Cal. App. 3d 407, 188 Cal. Rptr. 781 (1983) (parents refused to give consent to surgery for child with Downs syndrome); Hollander, *Euthanasia and Mental Retardation: Suggesting the Unthinkable*, 27 Mental Retardation 53 (1989); Wolfensberger, *The Killing Thought in the Eugenic Era and Today: A Commentary on Hollander's Essay*, 27 Mental Retardation 63, 64 (1989).

The guardians suggest, however, that the State could intervene if such decisions were "irrational and abusive." P.B. at 39 n.24. They thus concede that the State through its legislative or judicial functions may intervene to protect the best interests of principals in *some* cases. But if Missouri could legitimately decide as a matter of state policy and contrary to a surrogate's personal judgment that, for example, a principal's best interests are furthered by educational or rehabilitative services, the provision of pain killers, or ordinary nursing care, then surely the State might also conclude that Ms. Cruzan's best interests are served by continuing to provide her nutrition and hydration necessary to sustain her life.

The guardians' claim that Ms. Cruzan has been denied the "right" to have an "appropriate surrogate decisionmaker" decide that she should die by malnutrition and dehydration is, from this perspective, plainly misconceived. The "appropriate surrogate decisionmaker" for incapacitated adults like Ms.

Cruzan is finally the civil authority with ultimate jurisdiction over her person — the Missouri Supreme Court — and it has decided that she should not die in this fashion.

The guardians can make no superior claim to the authority of the Missouri Supreme Court in this regard. Guardianship has been, from its very inception, a creature of the State. In early medieval England, guardianship of the person and property of people with mental disabilities originally vested in the lord of the manor. S. Brakel, J. Parry & B. Weiner, *The Mentally Disabled and the Law* 369 (3d ed. 1985) [hereinafter *"The Mentally Disabled and the Law"*]. In the fourteenth century, the duty of caring for people with mental disabilities or illnesses was assumed by the Crown, which delegated the responsibility to the Chancellor. *Id.* (citing *De Praerogativa Regis*, 17 Edw. 2, cs 9, 10 (1324)). Chancery courts thus assumed the duty to determine whether a person was so incapacitated that he or she required appointment of a committee of the person, and they maintained the duty of supervising and controlling the committee to guard against abuse of the person or the person's interests. *Id. See also* S. Herr, *Rights and Advocacy for Retarded People* 9-15 (1983). "For the lord chancellor is, by right derived from the crown, the general and supreme guardian of all infants, as well as idiots and lunatics; that is, of all such persons as have not discretion enough to manage their own concerns." 1 W. Blackstone, *Commentaries** 463.

In the United States, the same jurisdiction over incapacitated persons was assumed by the courts of equity; ultimate authority was vested in the people rather than the Crown. *The Mentally Disabled and the Law* 369 (citing 2 L. Shelford, *A Practical Treatise on the Law Concerning Lunatics, Idiots, and Persons of Unsound Mind* (1833); 2 J. Reeves, *History of English Law* 307-8 (1814)). *See also* 2 J. Kent, *Commentaries** 226. This power of the *parens patriae* ("parent of the country") emanates from the State's traditional role as sovereign and guardian of persons under legal disabilities. *Black's Law Dictionary* 1003 (5th ed. 1979); *State ex rel Standefer v. England*, 328 S.W.2d 732, 738 (Mo. Ct. App. 1959). The authority inherent in equity courts was later codified in state guardianship laws (*e.g.*, Mo. Ann Stat. §§ 475.010 to 475.480 (Vernon 1956 & Supp. 1989)). *See The Mentally Disabled and the Law* 370 (citing *In re Estates of Vicic*, 79 Ill. App. 3d. 383, 398 N.E.2d 420 (1979)). *See also* 39 Am. Jur. 2d *Guardian and Ward* § 24 (1968 & Supp. 1989). Courts retain the duty to supervise guardians to assure that the guardians act in the best interests of their wards. *Standefer*, 328 S.W.2d at 738; *In re Hymes*, 102 Misc. 2d 821, 823, 424 N.Y.2d 608, 610 (Sur. Ct. 1979); Mo. Ann. Stat. §§ 475.110, 475.120(2)(3) (Supp. 1989); 39 Am. Jur. 2d *Guardian and Ward* § 62 (1968 & Supp. 1989). Guardians are themselves officers of the court. *In re Cordes' Estate*, 116 S.W.2d 207, 209 (Mo. Ct. App. 1989); *Snyder v. United States*, 134 F. Supp. 319, 322 (W.D.N.C. 1955).

Case law emphasizes the guardian's inferior relationship by affirming that the court with jurisdiction over a guardianship matter is "the superior guardian." 39 Am Jur. 2d *Guardian and Ward* § 1 (1968) (citing *In re Duren*, 355 Mo. 1222, 1229, 200 S.W.2d 343, 347 (1947); *Grayson v. Linton* 63 Idaho 695, 701, 125 P.2d 318, 320 (1942)). A guardian's authority is civil in origin, not personal; the guardian has no authority other than that vested by civil authority. *Trenton Trust v. Western Surety*, 599 S.W.2d 481, 489 (Mo. 1980); *Scott v. Royston*, 223 Mo. 568, 609, 123 S.W. 454, 466 (1909). This authority is subsidiary to the State's and therefore must be informed by objective evaluations of the best interests of wards by the State.

A state might choose to delegate to guardians the authority to terminate life-sustaining treatment or care. *See, e.g., In re Quinlan*, 70 N.J. at 42, 355 A.2d at 664. A state might instead subject such decisions to judicial review without dispositive regard to a guardian's views. *See, e.g., Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 758-59, 370 N.E.2d 417, 434-35 (1977). Or, as in the present case, a state might choose to scrutinize closely the care provided to protect

particularly vulnerable persons or to further the policies of specific state statutes. *See also, e.g., In re Conroy*, 98 N.J. 321, 381-84, 486 A.2d 1209, 1240-42 (1985).

Our law and tradition have never dictated a pre-ordained distribution of powers between civil authority and guardian. They have required only that the civil authority and the guardian that it appoints act in a ward's best interests — with final power to determine what those best interests are resting with the civil authority. Surely, if a guardian cannot "seek admission of his ward to a mental health or mental retardation facility for more than thirty days for any purpose without court order" (Mo. Ann. Stat. § 475.120(5) (Supp. 1989)), then guardians cannot legitimately claim that they should have unreviewable discretion to order the deaths of their wards by dehydration and malnutrition.

Aware of the weakness of claiming a right for a guardian to exercize Ms. Cruzan's constitutionally recognized rights, the guardians instead stress the parental rights and familial interests of Mr. and Mrs. Cruzan, appointed as guardians in this case. P.B. at 22-29.

If Ms. Cruzan were an unemancipated minor, then they could have asserted independent, constitutionally recognized rights to her custody and control as parents. But Ms. Cruzan was 25 years old and married at the time of her accident. She was an independent adult. Her parents could not then and can not now claim any special constitutional prerogative over her. They may have a prior claim to be appointed her guardians and, in practice, their decisions might be given a certain deference because of their relationship to her. Their legal authority over her is not, however, broader in scope than that of any other legal guardian — whether family member or stranger.

In any case, the guardians' assertion that "family decisionmaking" should govern withdrawal of life-sustaining care from adult members, if accepted, would be practically unworkable in many cases. Guardians are often appointed precisely because

there is conflict within or neglect by the family regarding the interests of an incapacitated member. *See, e.g., In re Guardianship of Phillip B.*, 139 Cal. App. 3d 407, 188 Cal. Rptr. 781 (1983) (court determined that biological parents were not appropriate guardians for minor and that the court had jurisdiction to determine who will act in the ward's best interests). It is unclear for many incapacitated adults who should be properly designated as a representative of that person's "family" or what the relative decisionmaking authority of each member should be. These problems may be further compounded by divorce and remarriage within families, alienation and hostility among family members, the self-interest of some family members, and the now common phenomenon of relocation of family members at wide distances. All of these considerations may make the maintenance of the continuing, intimate family relations suggested by the guardians here improbable or delusory.

And what of the many older incapacitated people and people with mental retardation, illnesses, or other disabilities who have no families or have been abandoned by them? *See, e.g., Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 731, 370 N.E.2d at 417, 420 (1977)(family of institutionalized 67-year-old man with severe mental retardation refused to become involved in decision concerning consent to medical treatment or any aspect of his life).

Moreover, the guardians' appeal to family decisionmaking authority suggests either that family members who have been appointed guardians should have special powers to withdraw life-sustaining care that guardians unrelated to the incapacitated person do not, or that unrelated guardians should be regarded as though they were family members and have the same authority to withdraw such care.

The former argument, if accepted, would apparently render the guardianship statutes of every jurisdiction unconstitutional for failure to provide special latitude to family members who have been appointed guardians. It would demand a dual system of guardianship in which guardians who are family

members might withdraw life-sustaining care from wards at will, while those who are unrelated to their wards could not.

The latter argument, if accepted, would impute to strangers, institutions, and bureaucrats the same kind of intimate relationship that inheres to the family, bestowing upon them whatever privileges are acknowledged under the Constitution to arise from common blood or marriage. Public guardians seek the same authority that Ms. Cruzan's guardians here seek. *See, e.g., In re Prange*, 520 N.E.2d 946 (1988), *vacated*, 527 N.E.2d 303 (Ill. 1988); *Rasmussen v. Fleming*, 741 P.2d 674 (Ariz. 1987). To bestow upon them the authority to withhold or withdraw life-sustaining care from their wards at will and without court supervision would pose unprecedented danger to the lives and well-being of the many incapacitated persons who are alone, abandoned, or unloved — and who could then rely only on often indifferent bureaucracies to maintain their well-being and their very lives. *See Parham v. J.R.*, 442 U.S. at 637-39 (Brennan, J., concurring in part, dissenting in part).

The guardians improperly rely on an abstract, generalized, familial interest in making decisions regarding their family members extrapolated from the decisions of this Court in other contexts to urge that it endows constitutional protection on familial decisions to deprive adult family members of life-sustaining care. To the contrary, our consistent law and tradition do not vest families with ultimate authority to determine the best interests of incapacitated adults. From the English Crown, to chancery court, to equity court, and through the guardianship statutes of the several states, the final authority over incapacitated adults has always been understood to reside with civil authority exercising inherent or statutorily codified *parens patriae* power — as the Missouri Supreme Court did in this case. *See also, e.g., In re Storar*, 52 N.Y.2d 363, 381, 438 N.Y.S.2d 266, 275, 420 N.E.2d 64, 73, *cert. denied, sub. nom. Storar v. Storar*, 454 U.S. 858 (1981).

There is no federal constitutional basis upon which to undercut this authority. To do so would fly in the face of a long legal tradition that has attempted to protect incapacitated people

through court supervision of guardians and that has flatly denied guardians and other surrogates final authority over their persons or property.

Ms. Cruzan unquestionably retains rights or liberty interests in her incapacitated state. But because she is physically and mentally unable to issue her own instructions, true respect for her rights and interests can only be manifested through an objective assessment of her best interests. The Missouri Supreme Court's evaluation of Ms. Cruzan's best interests is consistent with the Constitution and does not encroach upon any of her constitutionally protected interests.

III. The State May Properly Assert An Unqualified Interest In The Protection Of Life Regardless Of Degree Of Disability.

The Missouri court asserted that Missouri's "unqualified interest" in the preservation of life, together with Ms. Cruzan's liberty interest in accepting treatment and the relatively nonburdensome and beneficial nature of her care, warranted continuation of her feeding and hydration. *Cruzan*, 760 S.W.2d at 420. The court properly rejected a rule that discounts the state's interest in life on the basis of an assessment of its "quality." *Id.* In contrast, the guardians assert that such an unqualified interest prevents "quality of life" assessments that are "critical to preservation of individual liberty." P.B. at 38.

The freedom to implement decisions made by persons relating to the quality of their lives and circumstances is implicit in the liberties guaranteed by the Constitution. But the guardians' claim is relevant to the controversy now before this Court *only* if the Constitution demands that the state's interest in the preservation of life *must* diminish as "quality of life" declines.

The implications of such a proposition deeply disturb your *amici*, who represent and seek to improve the quality of opportunities for people with disabilities and their families. It plainly suggests a constitutionally imposed, sliding-scale standard of

treatment and care that devalues the lives and well-being of persons with disabilities and others who fail some notion of "quality control."

If the Constitution requires that the state's interest in the preservation of life must be entirely discounted for all persons like Ms. Cruzan, then why should it not also be discounted for others with disabilities? And if the state's interest in life itself must be so discounted, then why not in relation to the entire range of state interests that support the various social and economic laws intended to improve the lives and well-being of the population?

The guardians dismiss such concerns by implying that "irrational" quality assessments would be subject to judicial review. P.B. at 39 n.24. But the sad history of neglect and abuse of persons with disabilities is far too fresh for your *amici* to take comfort in such bland reassurances. *See* U.S. Comm'n on Civil Rights, *Medical Discrimination Against Children With Disabilities* 23-25 (1989); Herr, *Civil Rights, Uncivil Asylums, and the Retarded*, 43 U. Cin. L. Rev. 679, 697-98 (1974); Burgdorf & Burgdorf, *A History of Unequal Treatment: The Qualifications of Handicapped Persons as a "Suspect Class" Under the Equal Protection Clause*, 15 Santa Clara L. Rev. 855 (1975); S. Herr, *Rights and Advocacy for Retarded People* 18-36 (1983).

A constitutionally required "quality of life" assessment could not be confined only to those persons as seriously disabled as Ms. Cruzan without relying upon arbitrary distinctions between her condition and other impairments that cause permanent mental disabilities. Ms. Cruzan was held to be in a "persistent vegetative state," which simply denominates a set of characteristics somewhere on the continuum between full consciousness and total unconsciousness. There is no constitutional basis for drawing a bright line on this continuum at one point or another. Such a distinction would stand on the shifting sands of somewhat arbitrary medical categories, classifications, and assessments based on changing diagnostic and technological expertise and developments.

Medical science may inform us whether the physical basis for consciousness exists in light of observable phenomena, at least as the phenomenon of consciousness is commonly understood. "Consciousness" is not, however, a thing that can be easily quantified or understood in its fullness, complexity, or mystery. Ms. Cruzan and those with similar conditions may not be conscious in the same sense that those who read this Brief may be. Whatever loss of "consciousness" they may have is, in another sense, simply a measure of their disability. But where in the Constitution is the level or, indeed, the existence of consciousness deemed a prerequisite to the assertion of a state interest in the protection of the lives of human beings?

The same "unqualified" state interest in the protection of human lives asserted by the Missouri Court supports the homicide codes of the several states. Neither the common law nor any state statute has ever recognized that taking the lives of a class of human beings is justified or excused on account of the biological status of persons whose lives are taken. From this perspective, the Missouri court was not only justified to assert an unqualified state interest in protection of human life, it was perhaps obliged to do so.

IV. To Authorize Witholding Of Feeding And Hydration From Ms. Cruzan Would Necessarily Authorize Withholding Other Equivalent Or More Socially Burdensome Forms Of Care From People With Significant Mental Disabilities.

The Missouri court "refuse[d] to succumb to the semantic dilemma created by medical determinations of what is [medical] treatment. . . ." *Cruzan*, 760 S.W.2d at 423. "The issue is not whether the continued feeding and hydration of Nancy is medical treatment; it is whether feeding and providing liquid to Nancy is a burden *to her*." *Id.* (emphasis in original). Indeed, whether or not feeding and hydration by tube is categorized as "medical treatment" is constitutionally irrelevant. The liberty interest that requires deference here is the freedom to accept

or to reject bodily intrusions of *any* form — whether proposed under the aegis of a physician, nurse, rehabilitation therapist, or layman.

The issue thus before this Court is not simply whether Ms. Cruzan's guardians may withhold feeding and hydration provided by tube to her. It is whether the Constitution commands the State to empower surrogates to withhold or withdraw any and all forms of treatment or care from incapacitated persons — or at least those forms deemed similar to feeding and hydration by tube.

If surrogates may at will withhold or withdraw such a beneficial and minimally burdensome form of life-sustaining care as tube-feeding, then it would follow that surrogates would also be constitutionally authorized to order the withholding from incapacitated persons of a large number of treatments and services necessary to the well-being, rehabilitation, or independence of people with disabilities. Many forms of care commonly given to persons with disabilities are far more "intrusive" or "burdensome" than feeding and hydration by tube.

If Ms. Cruzan were not turned with some frequency, then she would quickly develop decubitus ulcers (bed sores) that would, in time, result in infections. Left untreated, they would cause her death. If her room were not heated in the winter, then she might die of hypothermia. Both ordinary nursing care and environmental maintenance require some level of technical expertise and may be as costly, intrusive, or burdensome to others as the enteral feeding the guardians wish to withhold from her. Yet if the guardians are constitutionally authorized to withhold food and fluids from their ward, then they might just as easily decide to decline her nursing care or room temperature maintenance.

It is generally no more difficult to provide sustenance by tube to persons like Ms. Cruzan than through the usual manner in which food and drink is prepared and provided either in a

hospital or at home. Complications may arise in the delivery of sustenance by tube that require medical attention. But this is true with regard to almost any mode of delivery, including eating by mouth, or any type of diet. And if persons like Ms. Cruzan are incapable of feeling pain, as the guardians assert (P.B. at 27), then tube-feeding cannot burden them in this regard. Feeding and hydration by tube through a gastrostomy, in any event, generally causes no significant pain, discomfort, or complications. Office of Technology Assessment, Congress of the U.S., *Life-Sustaining Technologies And The Elderly* 282 (1987).

Many people with disabilities may be able to swallow, but they are unable to secure food or liquids, prepare them for consumption, or lift them to their mouths. Without the assistance of others, whether described as "medical" or not, these people would die just as surely as Ms. Cruzan will if the guardians are authorized to carry out their proposal. Perhaps there are meaningful distinctions between these forms of care; perhaps not. What is certain is that the Constitution does not distinguish between them, and the Missouri court should not be faulted for likewise refusing to do so.

So anxiously do the guardians and their supporting *amici* assert Ms. Cruzan's right to refuse treatment that they would sacrifice to it her right to *receive* humane treatment, disregarding any requirement of a balanced judicial assessment of the duty of care owed to persons with disabilities. Their concept of personal autonomy is so expansive that it would survive even when the potential for its autonomous exercise is no longer present. And those for whom such personal autonomy is claimed would be condemned to death by dehydration and malnutrition — a death that is neither swift nor dignified.[2]

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[2] *See Brophy v. New England Sinai Hospital, Inc.*, 398 Mass 417, 444 n.2, 497 N.E.2d 332, 641 n.2 (1986)(Lynch, J., dissenting in part) (citing trial court findings on effects of withdrawing nutrition and hydration):

> [His] mouth would dry out and become caked and coated with thick material. His lips would become parched and cracked. His tongue would swell,

(footnote continued)

It is a concept of autonomy that must be rejected by this Court.

V. The Missouri Supreme Court's Holding Is Consistent With The United States Constitution.

The Missouri Supreme Court struck a procedural and substantive balance of the individual, familial, and societal values at stake in this case. The issue before this Court is whether the United States Constitution demands some arrangement of values other than that of the decision of the Missouri court. Your amici argue that it does not and, indeed, that the Constitution strongly supports the Missouri court's decision.

A. The Missouri Supreme Court Properly Balanced Ms. Cruzan's Right to Be Free of Unwarranted Bodily Intrusions With Her Right to Live.

Ms. Cruzan has severe disabilities and requires total care. Nonetheless, this Court has affirmed that individuals with "a reduced ability to cope with and function in the everyday world . . . rang[ing] from those whose disability is not immediately evident to those who must constantly be cared for . . . have and retain their substantive constitutional rights." *City of Cleburne v. Cleburne Living Center, Inc.*, 473 U.S. 432, 442-47 (1985).

Footnote 2 continued

and might crack. His eyes would recede back into their orbits and his cheeks would become hollow. The lining of his nose might crack and cause his nose to bleed. His skin would hang loose on his body and become dry and scaly. His urine would become highly concentrated, leading to burning of the bladder. The lining of his stomach would dry out and he would experience dry heaves and vomiting. His body temperature would become very high. His brain cells would dry out, causing convulsions. His respiratory tract would dry out, and the thick secretions that would result could plug his lungs and cause death. At some point within five days to three weeks his major organs, including his lungs, heart and brain, would give out and he would die. The judge found that death by dehydration is extremely painful and uncomfortable for a human being. The judge could not rule out the possibility that Paul Brophy could experience pain in such a scenario. Paul Brophy's attending physician described death by dehydration as cruel and violent.

On one hand, therefore, Ms. Cruzan retains a fundamental right to live. On the other, she retains a right to be free of unwarranted bodily intrusions. The Missouri Supreme Court concluded that Ms. Cruzan's best interests weigh in favor of continued life sustained by nourishment. In view of the importance of her right to live and the contingent and subsidiary nature of any right against bodily intrusions, together with the comparative severity of harms should either right be denied, the Missouri court's balance is constitutionally faultless.

Because Ms. Cruzan is alive, she is a person who retains the right to live, as explicitly guaranteed by the plain language of the Fourteenth Amendment to the Constitution. The right to exist is essentially "the right to have rights." *Furman v. Georgia*, 408 U.S. 238, 290 (1972) (Brennan, J., concurring). Thus, any right against bodily intrusion is necessarily a lesser constitutional value than the right to live. Conversely, "death is the ultimate sanction." *Id.* at 286. Because of "its finality and enormity, death . . . is in a class by itself." *Id.* at 287. Life's preeminent value may thus override the value attached to the freedom from bodily intrusion, when the intrusion is for the purpose of sustaining life and preventing death. The justification is compelling: If Ms. Cruzan's right to reject bodily intrusion is deemed paramount, and food and fluids are withheld from her, then her right to exist — and thus her "right to have the right" against bodily intrusions, with all her other rights — would be extinguished by death.

This calculus underlies the best interests test typically applied to medical treatment decisions. It is employed in emergency treatment cases, when the patient's consent is practically unobtainable, and in those cases where a never-competent patient needs life-sustaining care. It is consistent with basic constitutional values and offends no constitutional guarantees.

The guardians argue in essence that Ms. Cruzan has no right to live that can be balanced against her right to be free of bodily intrusions because her life is not "meaningful". P.B. at 16, 39 n.

24. They describe her as "an incompetent person in a persistent vegetative state without hope of ever recovering cognitive interaction with the world around her." P.B. at Question Presented. In essence, they thus claim that Ms. Cruzan's permanent mental disability and supposed lack of "cognitive interaction" prevent "meaningful" life, which in turn negates any consideration of her right to live — while, paradoxically, they insist that she retains a right to refuse the life-sustaining care that she now receives.

Their view is logically inconsistent and conflicts with this Court's assertion in *Cleburne* that disability does not extinguish substantive constitutional rights. Surely, the United States Constitution does not stand for the proposition that people with permanent cognitive impairments have no right to live, although they nevertheless retain the right to reject care necessary to sustain their lives.

B. The Missouri Supreme Court's Holding Is Consistent With The Constitutional Guarantee Of Equal Protection.

The Equal Protection Clause of the Fourteenth Amendment "is essentially a guarantee that all persons similarly situated should be treated alike." *Cleburne*, 473 U.S. at 439. The Missouri court implicitly and correctly held that persons with permanent cognitive impairments were similarly situated with non-impaired persons with respect to the state's interest in preserving life. It also implicitly and correctly held that persons permanently unable to make medical decisions were differently situated from persons competent to make their own medical decisions with respect to the state's interest in protecting autonomy.

Governmental distinctions based on mental disability must be rationally related to a legitimate governmental concern. *Cleburne*, 473 U.S. at 446. Thus, "the state may not rely on a classification whose relationship to an asserted goal is so attenuated as to render the distinction arbitrary or irrational." *Id.*

The Missouri court refused to acknowledge a diminished state interest in preserving life based on the sole fact that persons in need of life-sustaining care are mentally incapacitated. Mental capacity has no bearing on whether nutrition and hydration will sustain life. Thus, it would be irrational to conclude that mental disability diminishes the state's interest in providing care that restores or supplants the ability to ingest nutrients. Moreover, denying persons with mental disabilities food or fluids solely because they lack some cognitive function would be discrimination based on "mere negative attitudes" against disability. *See, id.*, at 448. "[T]he law cannot, directly or indirectly, give [such biases] effect." *Palmore v. Sidoti*, 466 U.S. 429, 433 (1984).

There is, however, a rational basis for recognizing that mental incapacity alters the nature of the state's interest in and obligation to protect autonomous decisionmaking. It is impossible to elicit instructions from persons permanently unable to interact with others. The distinction the Missouri court implicitly drew between the liberty interests of competent persons and incapacitated persons is therefore neither arbitrary nor irrational — it was necessary. The Missouri court thus reasonably concluded that the state's interest in and obligation to recognize an autonomous liberty interest was limited to discovering whether Ms. Cruzan had expressly exercised her right to choose or to refuse food and fluids before her incapacity. It was therefore constitutionally reasonable for the Missouri court to refuse to permit the "exercise" of Ms. Cruzan's autonomy rights by her guardians when the court determined it was not in her best interests to die by dehydration and malnutrition.

VI. The Missouri Supreme Court Decision Is Supported By Federal And State Law And Policy.

Although not directly at issue in this case, federal law and policy strongly support the Missouri court's refusal to discount the state's interest in the preservation of life on the basis of

disability, as well as its refusal to sanction the withholding of food and fluids from Ms. Cruzan on account of her disability. The laws and policies of several states, including Missouri, also support the court's refusal to sanction Ms. Cruzan's death by dehydration or malnutrition.

A. The Missouri Supreme Court Decision Is Supported By The Plain Language And Policy Of § 504 Of The Rehabilitation Act Of 1973.

Section 504 of the Rehabilitation Act of 1973 provides in relevant part: "No otherwise qualified handicapped individual in the United States . . . shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." 29 U.S.C.A. § 794 (West Supp. 1989).

For purposes of § 504, a handicapped individual is defined as anyone who "(i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment." 29 U.S.C.A. § 706(8)(B) (West Supp. 1989).

Any standard that permits forgoing of treatment, food, or fluids based solely on the mental or physical disability of a person whose treatment wishes are unknown would contradict the intent expressed by the Rehabilitation Act. U.S. Comm'n on Civil Rights at 61-78. The policy preference and plain language of § 504 thus support the Missouri court's decision to maintain Ms. Cruzan's food and fluids and its refusal to authorize withholding them from her solely because she is disabled.

B. The Missouri Supreme Court Decision Is Supported By The Policy of The Child Abuse Amendments of 1984.

A Congressional standard for providing food and fluids to infants with disabilities was originally enacted as part of the

1984 Amendments to the Child Abuse Prevention and Treatment Act. *See* 42 U.S.C.A. § 5106a (West Supp. 1989). This law requires state child abuse agencies receiving federal funds to monitor, investigate, and remedy decisions to withhold necessary medical treatment and care from infants with disabilities. 42 U.S.C.A. § 5106a(b)(10) (West Supp. 1989). According to the regulations implementing this Congressional mandate, infants with disabilities must *always* be provided "appropriate nutrition and hydration." 45 C.F.R. § 1340.15(b)(2) (1988). Failure to provide food or fluids, even when an infant is terminally ill, permanently comatose, or when medical treatment is otherwise futile or "inhumane," would constitute "neglect" under the Amendments. *Id.* The statute and its regulations draw no distinction between food and fluids provided by tube or provided through any other means. *See* U.S. Comm'n on Civil Rights at 79-92.

State courts have frequently requested legislative guidance in cases such as the one before this Court. The Congress has provided such guidance, and it supports the decision of the Missouri Supreme Court. Congress has established a clear policy preference against withholding nutrition or hydration from infants with disabilities. The Missouri court's refusal to authorize the withholding of nutrition and hydration from an adult with disabilities is fully consistent, therefore, with Congressional policy.

C. The Missouri Supreme Court Decision Is Supported By Numerous Laws And Policies Of Several States.

Several "living will" and durable power of attorney for health care laws recognize that the administration of food and fluids is an exception to the "life-sustaining procedures" that may be withdrawn or withheld pursuant to these laws. Forty states and the District of Columbia have "living will" laws that permit persons to declare that life-sustaining treatment should be withheld or withdrawn from them under certain circumstances. But eighteen states specifically exclude food and fluids from "life-sustaining procedures" that can be forgone pursuant

to a "living will".[3] Four states provide that the existence of a "living will" does not affect the responsibility of the physician or health care provider to provide food and fluids for a patient's comfort care or alleviation of pain.[4] Two states do not allow food or fluids to be withheld if death would result from malnutrition or dehydration.[5] Two states provide for a specific indication in a "living will" declaration whether or not "artificially" provided food and fluids should be provided.[6] One state allows for an explicit statement of intent in this regard,[7] but where intent is not stated, then "reasonable medical practice" includes oral administration of food or water to a patient, who accepts it,[8] and the "mere existence of a declaration or appointment of proxy does not . . . create a presumption . . . that the declarant" would want food or fluids withdrawn or withheld.[9] The "living will" laws of the thirteen remaining states do not make any explicit reference to the provision of food and fluids.[10]

[3] Ariz. Rev. Stat. Ann. § 36-3201(4) (1986); Colo. Rev. Stat. § 15-18-103(7) (1987); Conn. Gen. Stat. Ann. § 19a-570(1) (West Supp. 1989); Fla. Stat. Ann. § 765.03(3) (West 1986); Ga. Code Ann. § 31-32-2(5)(A) (1985 & Supp. 1989); Haw. Rev. Stat. § 327D-2 (Supp. 1987); Ind. Code Ann. § 16-8-11-4 (Burns Supp. 1988); Iowa Code Ann. § 144A.2(5) (1989); Me. Rev. Stat. Ann. tit. 22, § 2921(4) (Supp. 1988); Md. Health-Gen. Code Ann. § 5-605(1) (Supp. 1988); Mo. Ann. Stat. § 459.010(3) (Vernon Supp. 1989). N.D. Cent. Code § 23-06.4-02(4) (Supp. 1989); N.H. Rev. Stat. Ann. § 137-H:2 (II) (Supp. 1988); Okla. Stat. Ann. tit. 63, § 3102(4) (West Supp. 1989); Or. Rev. Stat. § 97.050(3) (1987); Utah Code Ann. § 75-2-1103(6)(b) (Supp. 1989); Wis. Stat. Ann. § 154.01(5)(b) (1989); Wyo. Stat. § 35-22-101(a)(iii) (1988).

[4] Ark. Stat. Ann. § 20-17-206(b) (Supp. 1987); Mont. Code Ann. § 50-9-202(2) (1987); S.C. Code Ann. § 44-77-20(b) (Law Co-op. Supp. 1988); W. Va. Code § 16-30-3 (1985).

[5] Ill. Ann. Stat. ch. 110 1/2, para. 702, § 2(d) (Smith-Hurd Supp. 1989); Tenn. Code Ann. § 32-11-103(5) (Supp. 1988).

[6] Alaska Stat. §§ 18.12.010(c), 18.12.040(b) (1986); Idaho Code § 39-4504 (Supp. 1989).

[7] Adult Health Care Decisions Act, ch. 3, §§ 145B.03(2), 145B.04(6) 1989 Minn. Sess. Law Serv. 6, 7-8 (West).

[8] § 145B.13(2), 1989 Minn. Sess. Law. Serv. 6, 12 (West).

[9] § 145B.03(2), 1989 Minn. Sess. Law. Serv. 6, 7 (West).

The "living will" laws of the thirteen remaining states do not make any explicit reference to the provision of food and fluids.[10]

Eight states have durable power of attorney for health care laws, which permit persons to appoint surrogates to make their medical treatment decisions.[11] Of these, one state specifically excludes food and fluids from the category of "life-sustaining" procedures that can be withdrawn or withheld by a designated surrogate.[12] One state allows a person to decide specifically whether or not he or she should receive food and fluids.[13] One state excludes nutrition from the definition of "life-sustaining procedures" that can be withheld or withdrawn by a surrogate,[14] although the person can specifically decide whether or not to receive food and fluids.[15]

Two states have specific statutory provisions creating the presumption that *every* incompetent person wishes to receive food and fluids necessary to sustain life that applies unless the person clearly indicated otherwise or unless certain specified

[10] Ala. Code §§ 22-8A-1 to -10 (1984); Cal. Health & Safety Code §§ 7185-7195 (West Supp. 1989); Del. Code Ann. tit. 16, §§ 2501-2509 (1983); D.C. Code Ann. §§ 6-2401 to -2430 (1989); Kan. Stat. Ann. §§ 65-28.101 to -28.109 (1985); La. Rev. Stat. Ann. §§ 40:1299.58.1 to .10 (West Supp. 1989); Miss. Code Ann. §§ 41-41-101 to -121 (Supp. 1988); Nev. Rev. Stat. §§ 449.540 to .690 (1987); N.M. Stat. Ann. §§ 24-7-1 to -10 (1986); N.C. Gen. Stat. §§ 90-320 to -323 (1985); Tex. Rev. Civ. Stat. Ann. art. 4590h, 1-11 (Vernon Supp. 1989); Vt. Stat. Ann. tit. 18, §§ 5251-5262 (1987); Va. Code Ann. §§ 54.1-2981 to 2992 (1988 & Supp. 1989); Wash. Rev. Code Ann. §§ 70.122.010 to .905 (Supp. 1989).

[11] Cal. Civ. Code §§ 2430 to 2444 (West Supp. 1988); Idaho Code § 39-4505 (Supp. 1988); Ill. Ann. Stat. ch. 110, paras. 801-1 to -12 (Smith-Hurd Supp. 1988); Nev. Rev. Stat. §§ 449.800 to .860 (1987); Act of Aug. 2, 1989, ch. 914, 1989 Or. Laws 1752; R.I. Gen. Laws §§ 23-4.10-1 to -2 (Supp. 1988); Utah Code Ann. § 75-2-1106 (Supp. 1989); Vt. Stat. Ann. tit 14, §§ 3451-3467 (Supp. 1988).

[12] Utah Code Ann. § 75-2-1106 (Supp. 1989).

[13] Vt. Stat. Ann. tit. 14, § 3466(b) (Supp. 1988).

[14] Act of Aug. 2, 1989, ch. 914, § 1(9), 1989 Or. Laws 1752-1753.

[15] Act of Aug. 2, 1989, ch. 914, § 6, 1989 Or. Laws 1752, 1754.

and limited conditions exist.[16] Food and fluids cannot be withheld, however, if death would result from starvation or dehydration under one statute unless the person had clearly refused them prior to incompetence.[17]

Finally, statutes applicable to other contexts likewise demonstrate a clear preference for providing food and fluids to persons with disabilities. State child abuse statutes typically require that those with a duty of care toward a child provide the child with adequate sustenance.[18] In addition, state elder or adult abuse statutes provide that dependent older persons must be given adequate sustenance.[19] Finally, various state nursing home laws mandate that adequate sustenance be provided to residents.[20]

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[16] Okla. Stat. Ann. tit. 63, §§ 3080.3, 3080.4 (West Supp. 1989); Act of Aug. 2, 1989, ch. 914, § 16(1) 1989 Or. Laws 1752, 1756-1757.

[17] Okla. Stat. Ann. tit. 63, § 3080.4(B) (West Supp. 1989).

[18] Okla. Stat. Ann. tit. 10, § 1101(4) (West Supp. 1989). *See also, e.g.*, Alaska Stat. § 47.17.070(6) (Supp. 1989); Cal. Penal Code § 11165.2 (West Supp. 1989); Col. Rev. Stat. § 14-6-101(1) (1987); Fla. Stat. Ann. § 39.01(37) (West 1988); Fla. Stat. Ann. § 415.503(8)(f) (West Supp. 1989); Ga. Code Ann. § 19-14-2(4) (Harrison 1987); Ind. Code Ann. § 31-6-4-3(1), (2) (Burns 1989); La. Rev. Stat. Ann. 13:1600(2) (West 1983); Minn. Stat. Ann. § 609.378(a) (West 1987); Minn. Stat. Ann. § 626.556(2) (West Supp. 1989); Mo. Ann. Stat. § 210.110(5) (Vernon Supp. 1989); Mo. Ann. Stat. § 211.447(2)(2)(d) (Vernon Supp. 1989); N.J. Stat. Ann. § 9:6-1 (West Supp. 1989); N.J. Stat. Ann. 9:8.21(c) (West Supp. 1989); Okla. Stat. Ann. tit. 10, § 1130(B) (West 1987); Okla. Stat. Ann. tit. 21, § 845(B)(1) (West Supp. 1989); Pa. Stat. Ann. tit. 11, § 269-1(3) (Purdon 1965); R.I. Gen. Laws § 11-9-5 (1981); and V.I. Code Ann. tit. 5, § 2502(20) (Supp. 1989).

[19] Ala. Code § 38-9-5 (Supp. 1989); Ark. Stat. Ann. § 5-28-103 (1987); Cal. Welf. & Inst. Code §§ 15610(c)(4), (d) (West Supp. 1989); Del. Code Ann. tit. 31 § 3902(4) (1985); Mont. Code Ann. §§ 53-5-503(1), (2) (1989); Nev. Rev. Stat. § 200.5092.1(b) (1987); Or. Rev. Stat. §§ 163.200(1), (2) (1983).

[20] *See, e.g.*, Fla. Stat. Ann. § 400.141(5) (West 1986). Numerous state nursing home statutes prohibit abuse and neglect of nursing home residents, and failure to provide nutrition and hydration has been held to constitute

(footnote continued)

Plainly, developing state law and policy do not regard the provision of food and fluids by tube or otherwise as a matter solely within the discretion of institutions, guardians, or other surrogates. To the contrary, these laws and policies strongly support the judgment of the Missouri Supreme Court that food and fluids should not be withheld or withdrawn from dependent persons, at least not without their explicit and informed refusal to accept them.

Footnote 20 continued

"abuse and neglect" as defined under this type of statute. *State v. Serebin*, 119 Wis. 2d 837, 859-860, 350 N.W.2d 65, 76 (1984)(nursing home administrator was properly convicted under Wisconsin statute forbidding abuse or neglect of nursing home residents on grounds he failed to provide proper nutrition, which resulted in residents' serious dehydration and malnutrition).

CONCLUSION

Your *amici* represent families of people with disabilities, professionals who serve them, and people who themselves have disabilities. They join with the consensus of those legislatures and courts who cherish and protect the lives and well-being of people who are disabled and cannot speak for themselves. They urge this Court to sustain the judgment of the Missouri Supreme Court, thereby protecting the life of Ms. Cruzan and many other similarly vulnerable persons.

Respectfully submitted,

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Appendix

Appendix A
ARCUS

ARC Resolution on Cessation of Nutrition and/or Hydration

WHEREAS, debate is currently taking place concerning the appropriateness of withdrawing food and fluids from some persons labeled "comatose" or "in a permanent vegetative state" in order to cause death; and

WHEREAS, persons labeled "comatose" or "in a permanent vegetative state" may appear to share many characteristics with some persons labeled "profoundly mentally retarded"; and

WHEREAS, the Supreme Court's 1986 Baby Doe decision underscored and added to the medical vulnerability of certain persons experiencing significant disabling conditions; and

WHEREAS, purposefully causing death is the ultimate denial of civil and human rights of persons with mental retardation; and

WHEREAS, purposefully causing death based on assumption of mental functioning is the ultimate discrimination;

THEREFORE BE ITRESOLVED, that the ARC of the United States opposes the cessation of nutrition and/or hydration for the purpose of hastening or causing the death of persons with mental retardation.

Association for Retarded Citizens of the United States
Adopted October 25, 1986

Appendix B
TASH

TASH Resolution on Nutrition and Hydration

WHEREAS, there are an increasing number of decisions supporting the cessation of nutrition and hydration for individuals who are themselves unable to consent and have not by valid expression consented to such procedures;

WHEREAS, The Association for Persons with Severe Handicaps is committed to the value of all people regardless of severity of disability, and;

THEREFORE BE IT RESOLVED THAT: The Association for Persons with Severe Handicaps strongly opposes any cessation of nutrition and hydration for people who are incapacitated and that The Association for Persons with Severe Handicaps will seek to involve itself in litigation and legislation judged to have potential for setting precedents that will affect the rights of individuals who are incapacitated and at risk of loss of life and health without provision of hydration, nutrition, and medical treatment;

FURTHER BE IT RESOLVED THAT, The Association for Persons with Severe Handicaps strongly opposes approaches now advocated by many which authorizes third parties exercising substitute judgment to decide "on behalf" of an incapacitated person that the person's life is no longer "worth" living and strongly opposes any position that it would be in the best interests of a person to die rather than to live with a disability.

—Resolution passed at Board Meeting, November 15, 1986.

Appendix C
UHF

United Handicapped Federation Resolution

The Board of the UNITED HANDICAPPED FEDERATION, a disability rights coalition of twenty-eight groups with approximately 12,000 members in the State of Minnesota, approved this Resolution April 10, 1986:

BE IT RESOLVED that the United Handicapped Federation considers full *access* to nutrition and hydration, and to ordinary medical treatment, including antibiotics, whether administered by usual physical means or by artificial or technological assistance, to be a basic right of all persons, regardless of age, whether or not they have disabilities, and whether or not they are terminally ill.

FURTHER, the United Handicapped Federation recognizes that in some rare instances of terminal cancer or other severe illness, the provision of nutrition and fluids can be hurtful due to metabolic problems, even hastening death, and thus it may be medically and ethically appropriate to limit medical treatment and/or nutrition and fluids during the terminally ill patient's final days. (Please refer to *Nutritional Therapy in Advanced Cancer,* 78 Post Graduate Medicine 83 (1985)).

MOST IMPORTANT is the proper monitoring of all treatment and care during severe illness so that treatment and care are appropriately administered.